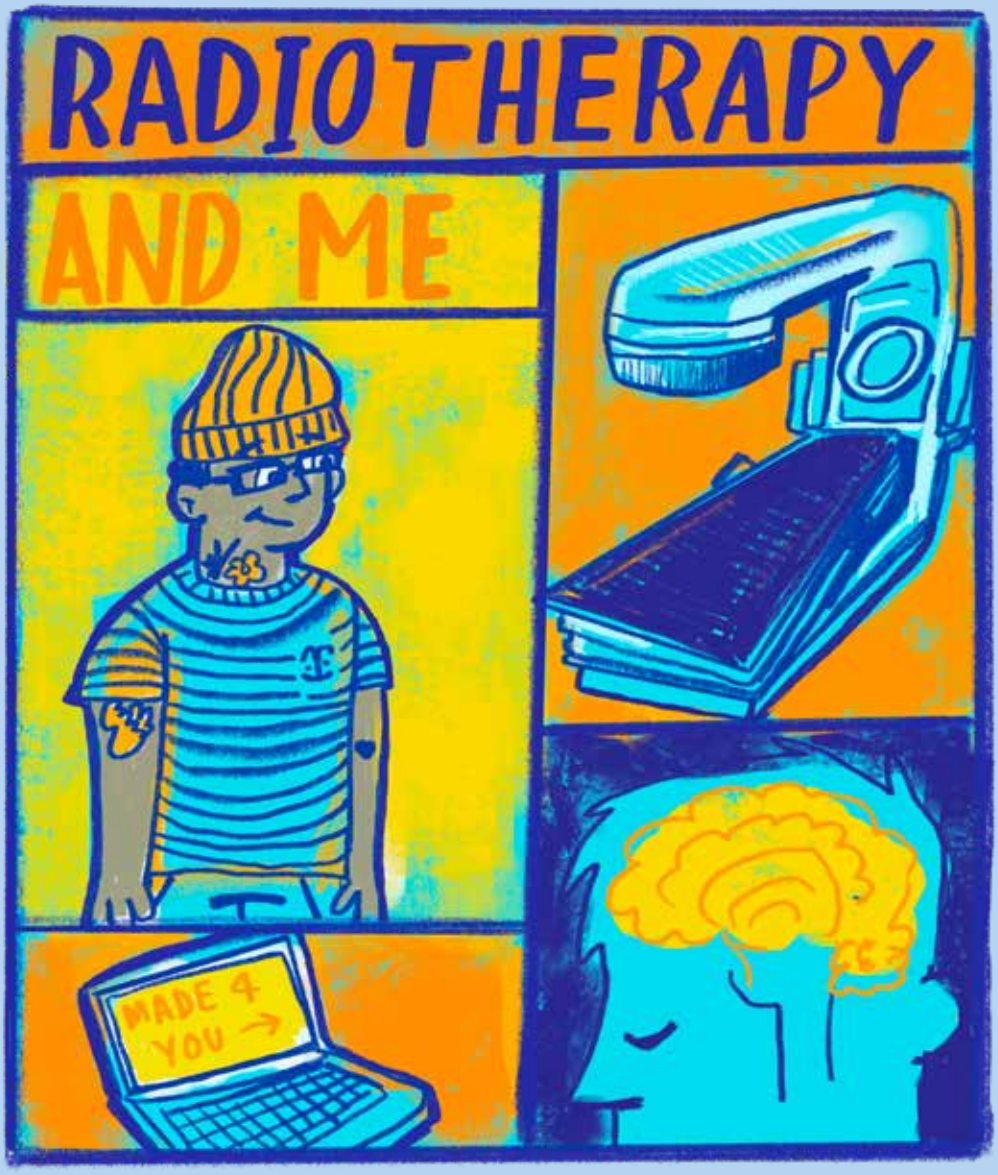
little brainstrust
the brain cancer people

RADIOTHERAPY AND ME

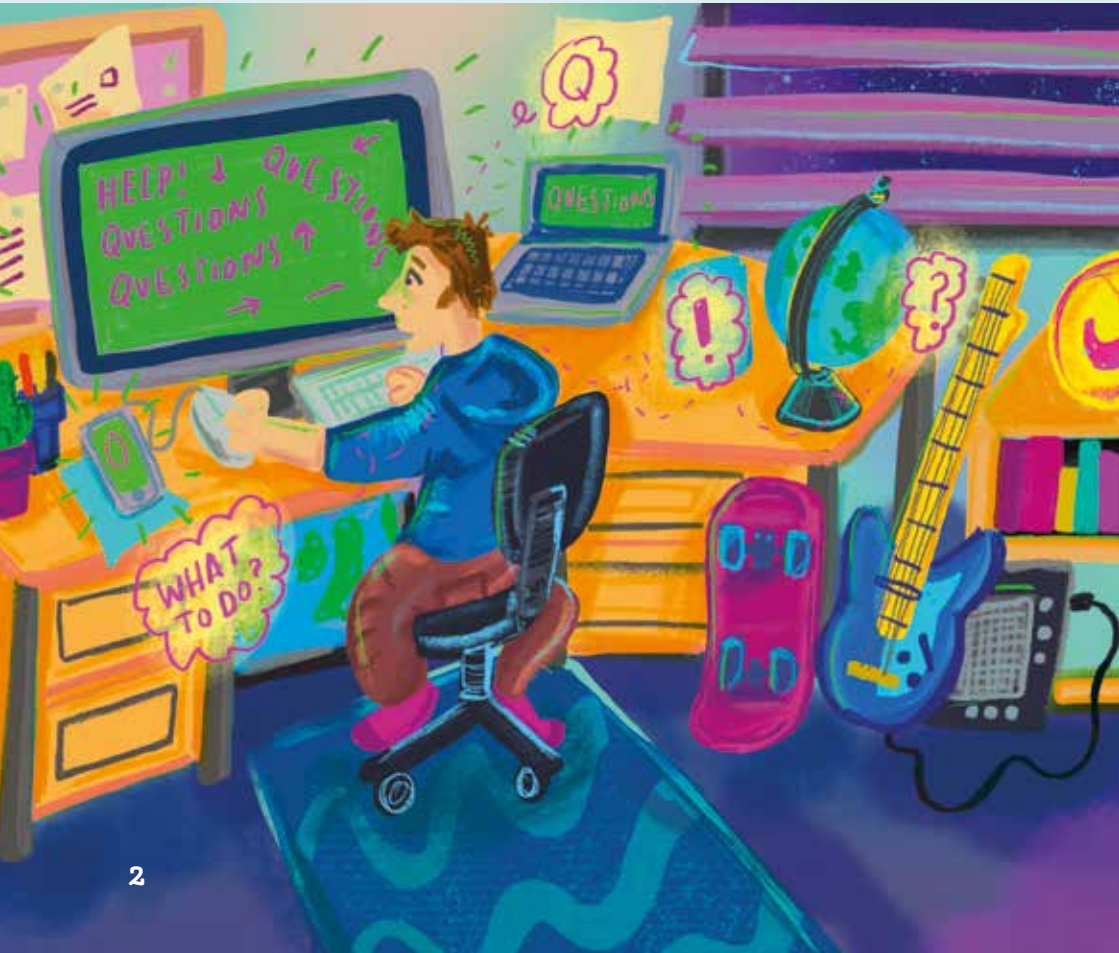


INFORMATION TO HELP YOU UNDERSTAND RADIOTHERAPY TREATMENT

CONTENTS

HELLO THERE!

WE KNOW YOU MUST HAVE A MILLION QUESTIONS AND A WHIRLWIND OF EMOTIONS



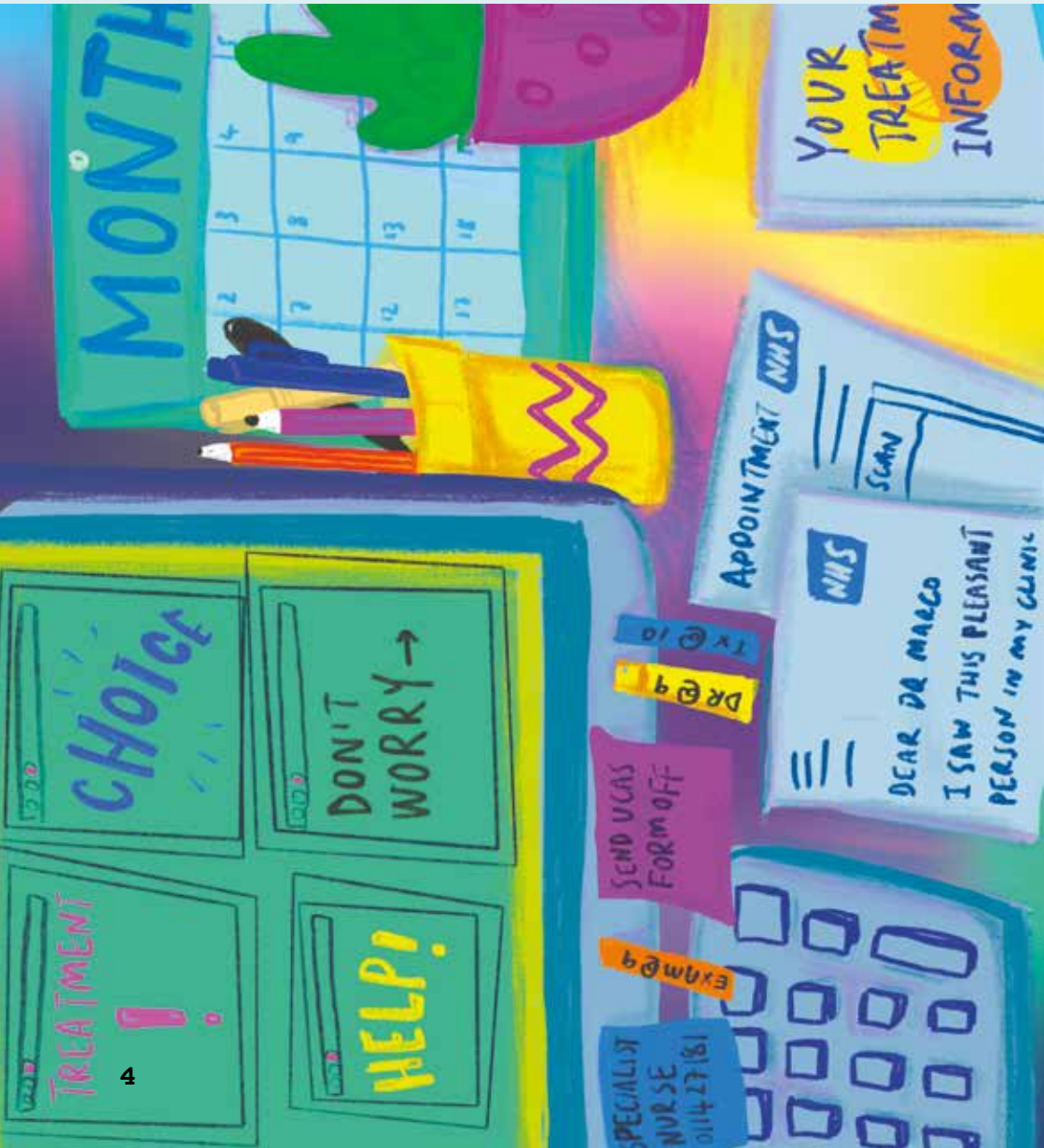
This guide is here to help you understand a little more about radiotherapy, with some medical language that you might hear. If there is anything you don't understand, ask us or a healthcare professional.

The term 'brain tumour' covers a wide range of diseases. Treating a brain tumour is complicated, and deciding what treatment is best can be difficult. It is important that you feel supported throughout your journey and that you are well informed about your options. There is a lot of information, so don't stress or try to finish it in one go.

Take your time, make notes and jot your questions down.

You may not feel in control, but you are the boss. So if something doesn't make sense or something doesn't feel quite right, talk to someone.

You are in control.



YOU ARE IN CONTROL.

REMEMBER YOU ARE NOT ALONE.

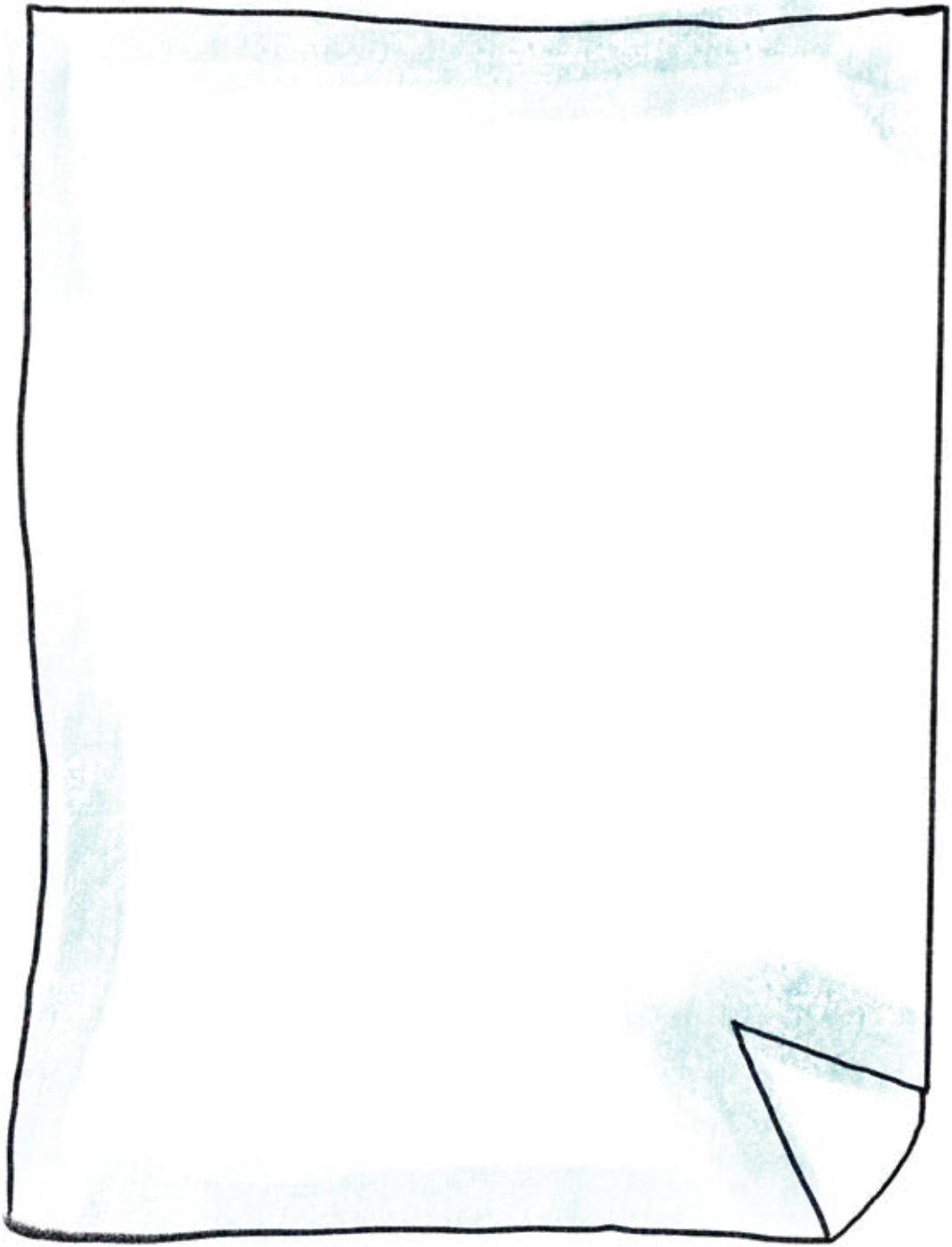
IF YOU EVER WANT TO TALK TO SOMEONE, JUST GIVE US A CALL ON

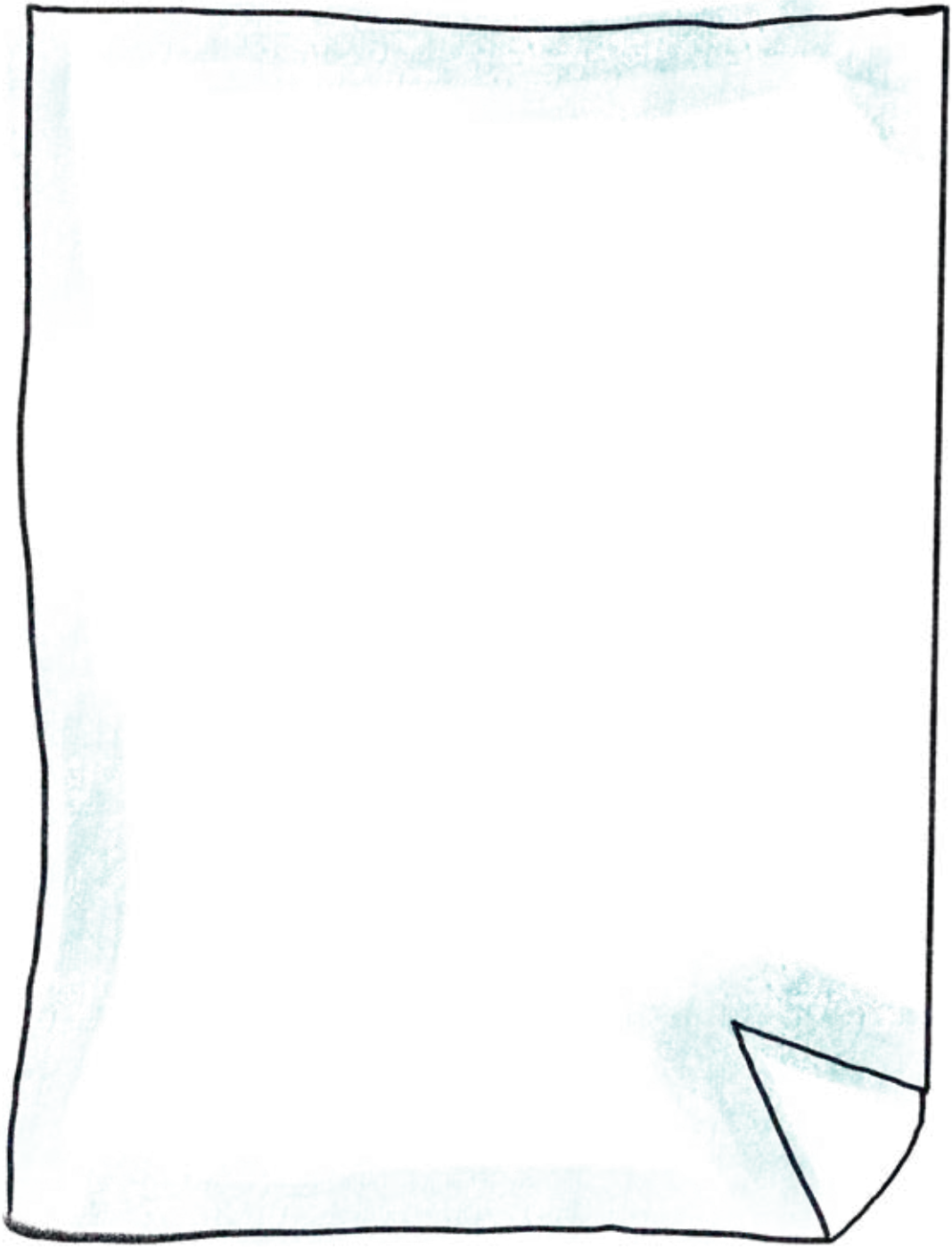
0 1 9 8 3 2 9 2 4 0 5

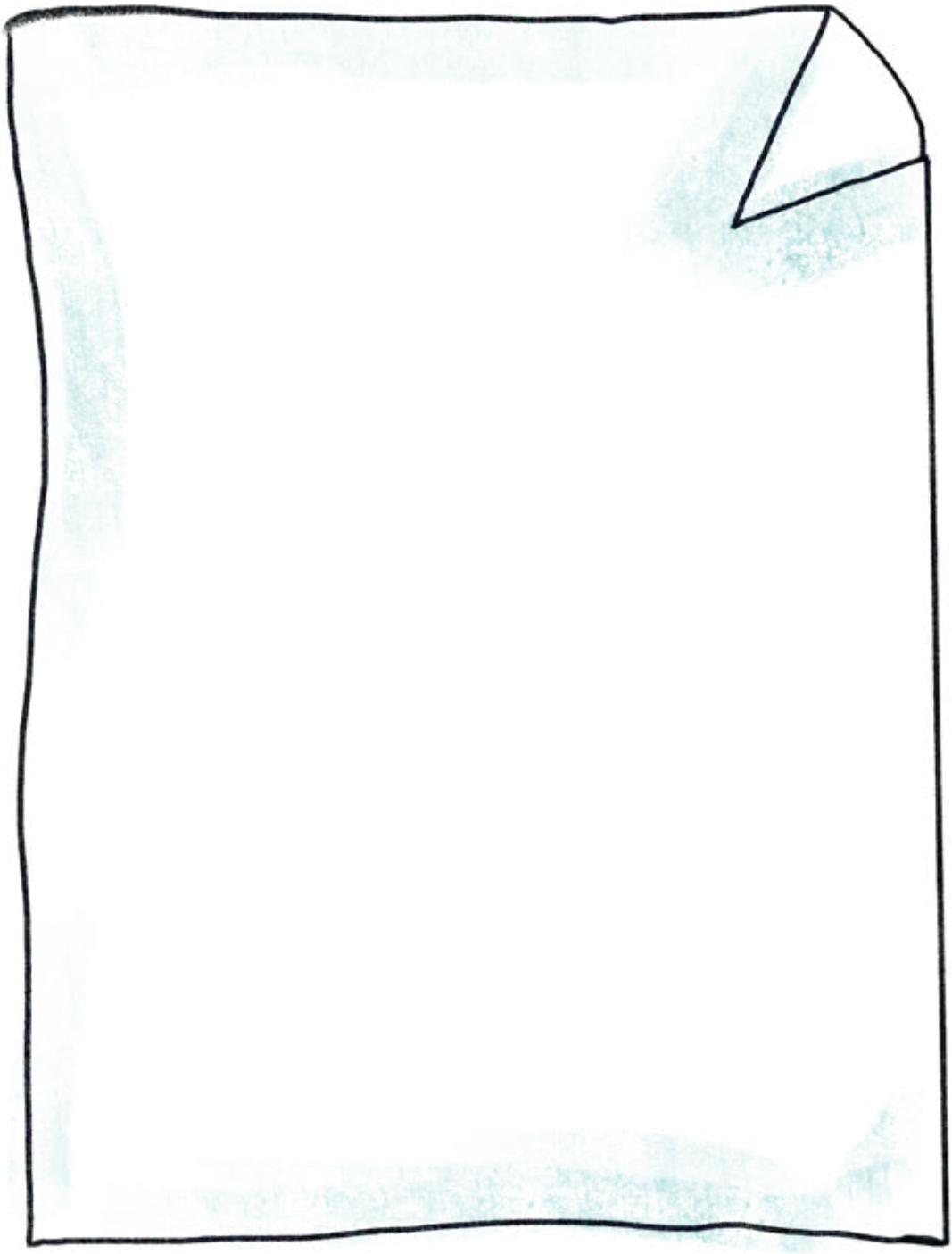
— OR —

EMAIL: hello@brainstrust.org.uk

JOT DOWN YOUR THOUGHTS HERE





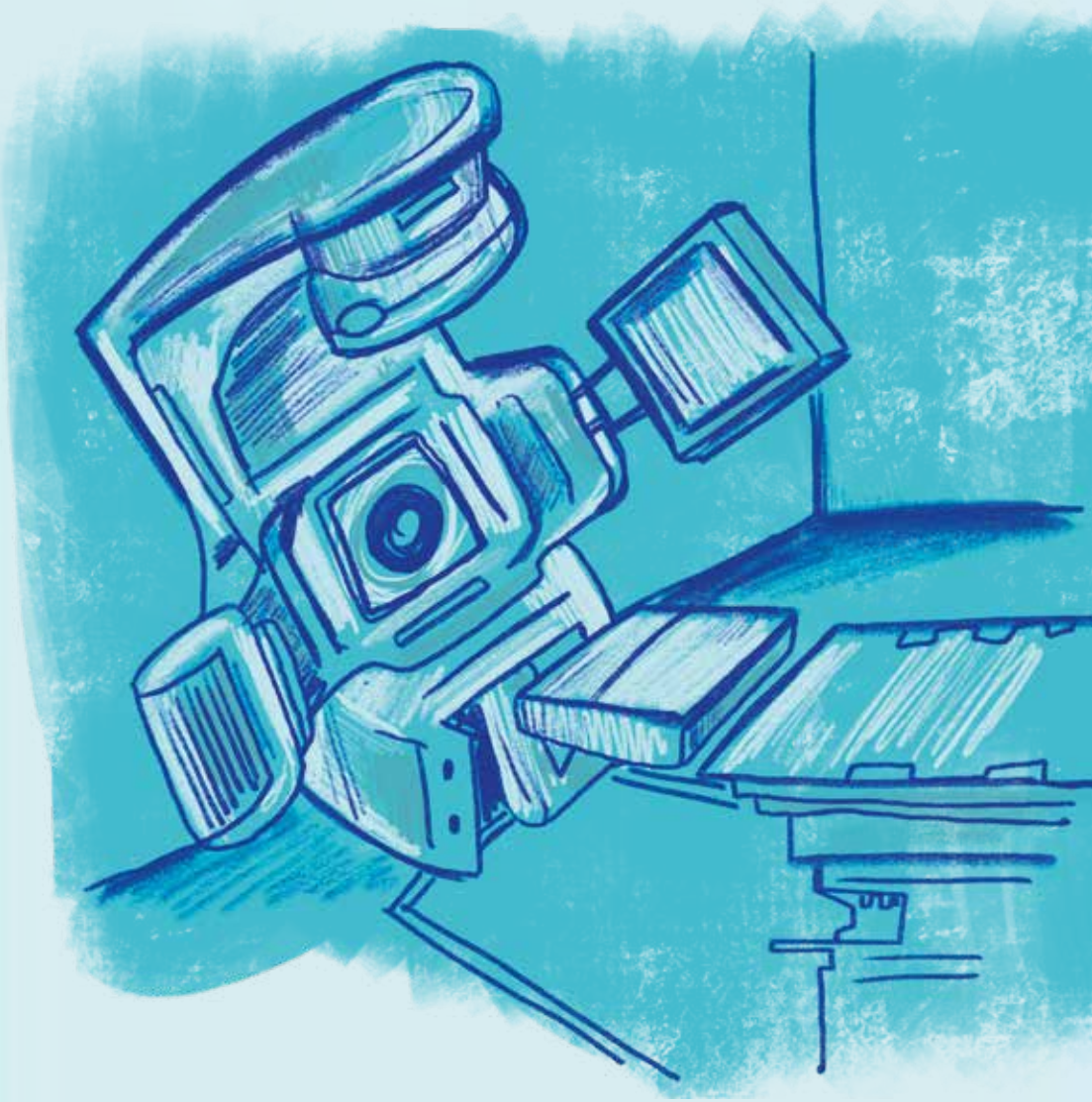


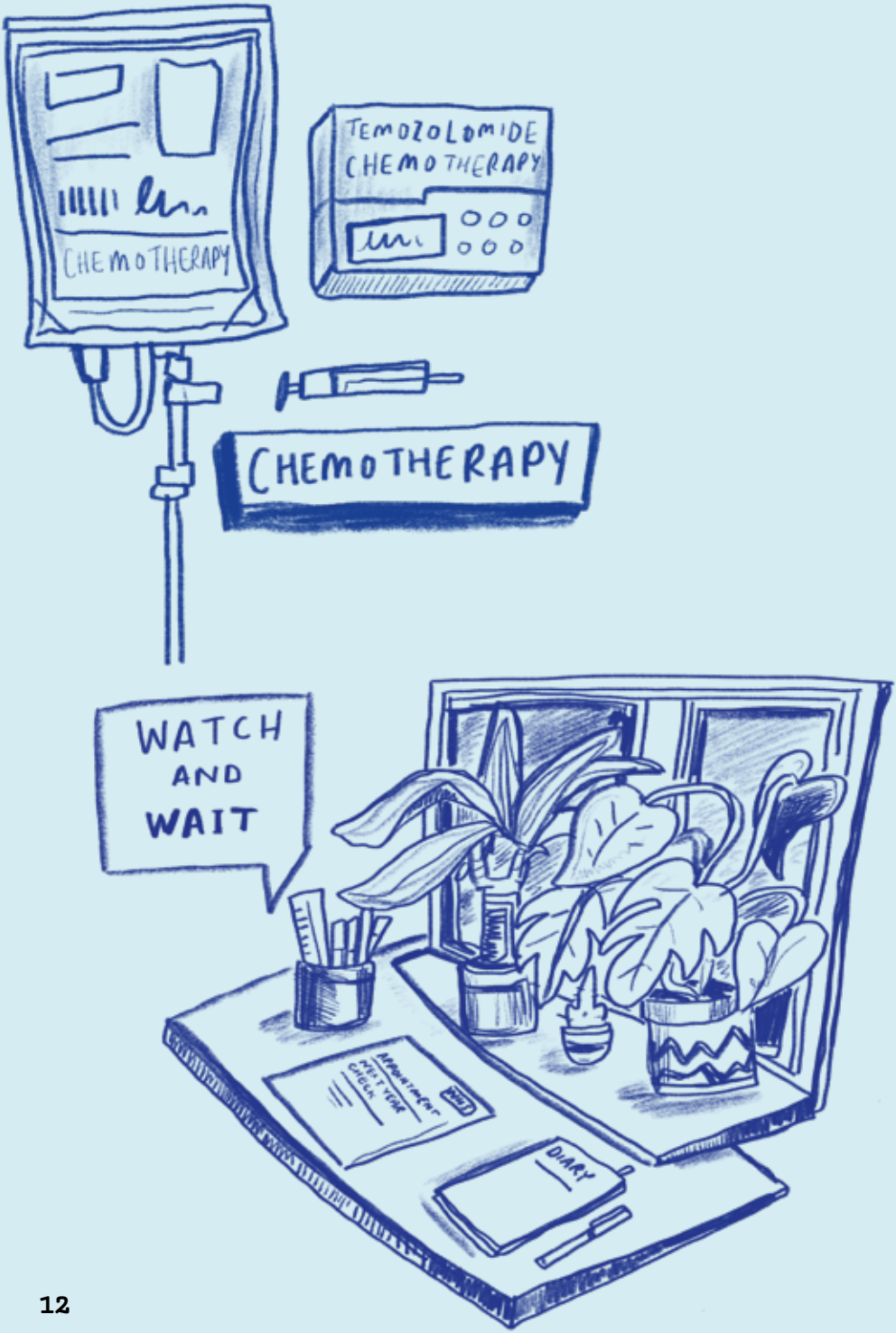
HOW IS A BRAIN TUMOUR TREATED?

The current options for treating a brain tumour include:

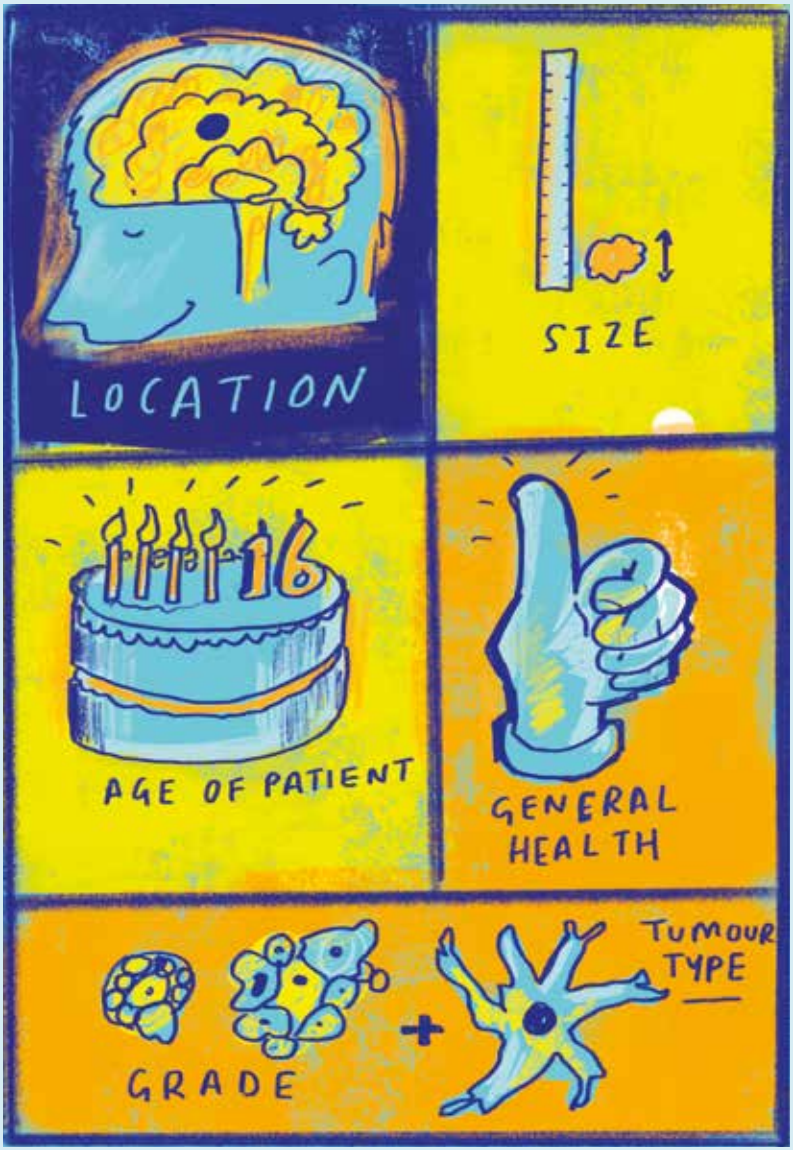
SURGERY

RADIOTHERAPY




CHEMOTHERAPY
TEMOZOLOMIDE
CHEMOTHERAPY
CHEMOTHERAPY
WATCH
AND
WAIT
APPOINTMENT
NEXT YEAR
CHECK
DIARY

MANY PEOPLE HAVE A COMBINATION OF TREATMENTS, AND THE CHOICE OF TREATMENT DEPENDS ON THE FOLLOWING:



What are my treatment choices?

Are there any choices available elsewhere that aren't available here?

Which course of treatment do you recommend for me?

Why? How does that treatment work?

What are the expected benefits of each kind of treatment?

What can I do to prepare for treatment?

Do I need to stay in the hospital?

If so, for how long?

What are the possible side effects?

How can side effects be managed?

How will treatment affect my normal activities?

Can I continue with my studies/hobbies/job?

What are the chances that I will have to learn how to walk, speak, read or write again after treatment?

Are there any clinical trials appropriate for me?

If there aren't, why not?

How can I get a second opinion?

What questions would you ask?

Your doctors are best placed to advise you about the most appropriate treatments for you. Along your journey, you may encounter different doctors who specialise in different treatments.

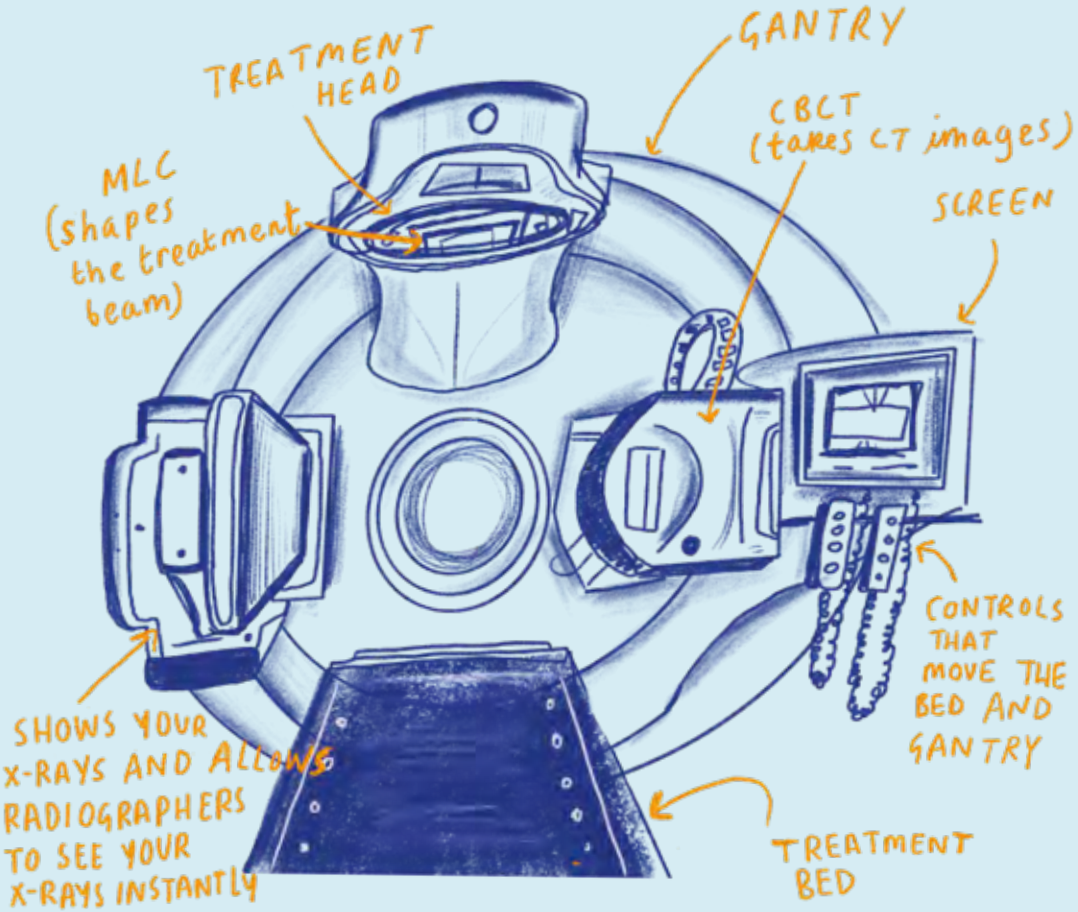
This can include clinical oncologists, who specialise in radiotherapy (sometimes referred to as radiation therapy). You may well have a specialised nurse who will support you throughout your whole journey.

This handbook is to help you understand the range of radiotherapy treatments that are currently available.

We know how confusing it can be, give *brainstrust* a call if you want to talk it through, on 01983 292 405, or drop us an email at hello@brainstrust.org.uk.

WHAT IS RADIOTHERAPY?

Radiotherapy uses high-energy radiation to destroy cancer cells. Radiotherapy is most commonly delivered through a machine called a linear accelerator (linac) and can also be referred to as external beam radiotherapy (EBRT).



Radiotherapy can be used before, after or instead of surgery.

The choice often depends on the purpose of the treatment, its effectiveness and the possible side effects and associated risks. Some people may also be given radiotherapy in combination with chemotherapy.

This will all be explained to you before you are asked to consent to any treatment. This is a good opportunity to discuss any concerns you may have.

How does radiotherapy work?

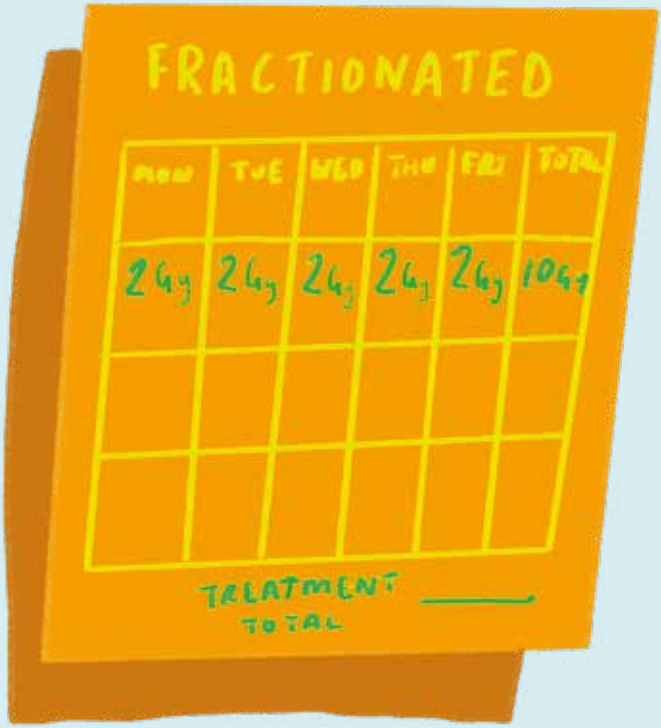
Radiotherapy damages the DNA in cells. Cancerous or abnormal cells are less able to repair themselves, which means they can die as a result of this damage.

DNA in healthy cells is also damaged in the process, but they are better able to repair themselves. Radiotherapy treatment is carefully planned to minimise damage to healthy cells.

FRACTIONATED RADIOTHERAPY

Fractionated radiotherapy is when radiation is divided into a number of smaller doses, called fractions. This allows healthy cells to recover between treatments.

It is also called external beam radiotherapy (EBRT), which is the most common method of radiotherapy used for people with brain tumours.



Sometimes radiotherapy is given as palliative treatment. This means it is used to control the symptoms of your brain tumour rather than treat the brain tumour.

Remember – palliative care is not end-of-life care. These are two very different stages, and you can lead a good quality of life for a long time when receiving palliative care.

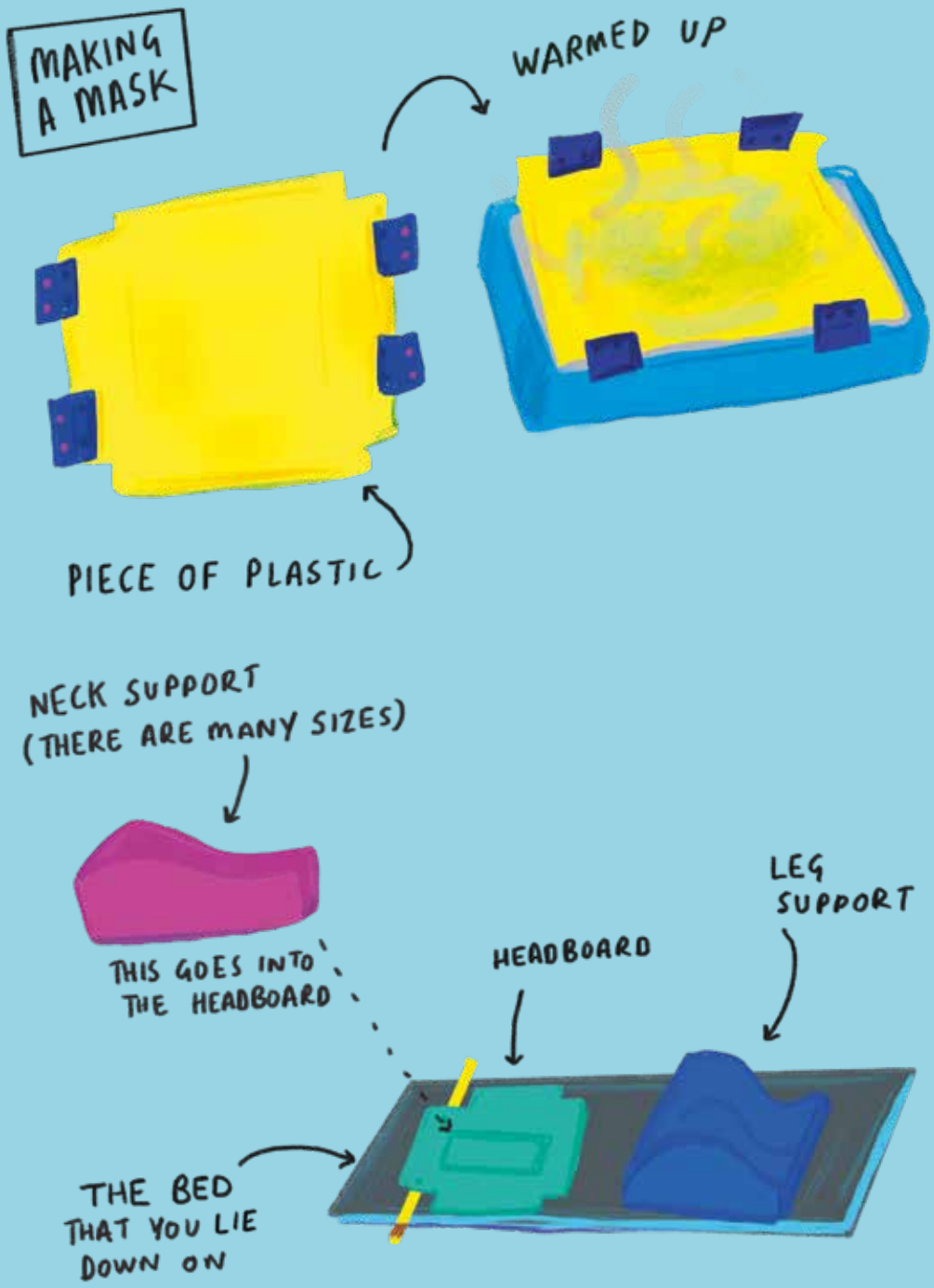
THERAPY RADIOGRAPHERS

The radiotherapy is planned and delivered by therapy radiographers. They are specialists in radiotherapy, and you will first meet them at the planning stage. They will also see you each day and will monitor your progress throughout your course of treatment. They are well placed to answer any questions you may have about treatment and any possible side effects. This includes any changes to appointments.

PLANNING

Planning radiotherapy can be quite complicated and can therefore take a few weeks.

Planning will begin with making a personalised mask to help keep you still and ensure the treatment is precise. This mask will be made from a sheet of plastic that is warmed, placed onto your head and moulded to fit you. Once the mask cools, it goes hard and sets, keeping your shape. There are lots of holes, so you are able to breathe easily.


MAKING A MASK
WARMED UP
PIECE OF PLASTIC
NECK SUPPORT (THERE ARE MANY SIZES)
THIS GOES INTO THE HEADBOARD
HEADBOARD
LEG SUPPORT
THE BED THAT YOU LIE DOWN ON

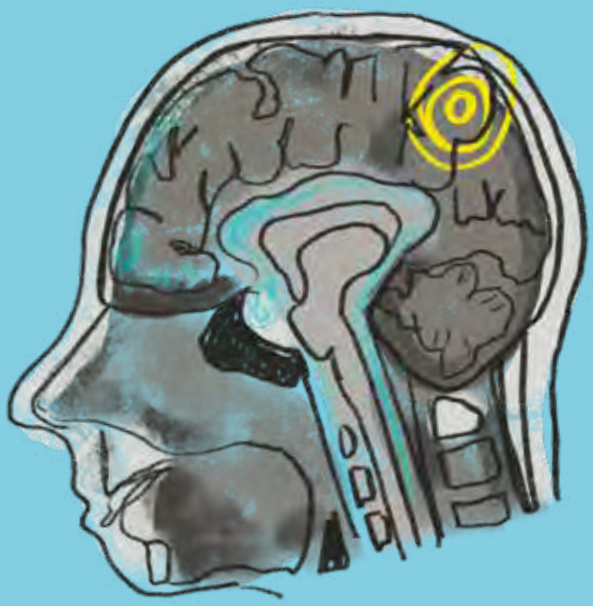

THE MASK IS COOLED AND MOULDED TO THE SHAPE OF YOUR FACE

You will then need to have a CT scan with the mask on, and in the treatment position. A CT scanner is a doughnut-shaped machine that you pass through while lying on the CT couch.

CT scans provide 3D images that show your exact shape and the shape, size and position of your internal anatomy. Once the scan is complete, your part in planning is over.

MARKS ARE DRAWN ON YOUR MASK TO HELP TO REPLICATE THIS POSITION THROUGHOUT TREATMENT

Some people, depending on the tumour type and location, may have an MRI scan with or without the mask to help with radiotherapy planning too.



The remainder of your planning involves using your images to identify the tumour and the healthy tissues, and finding the best way to target the tumour while minimising the dose to healthy tissues.

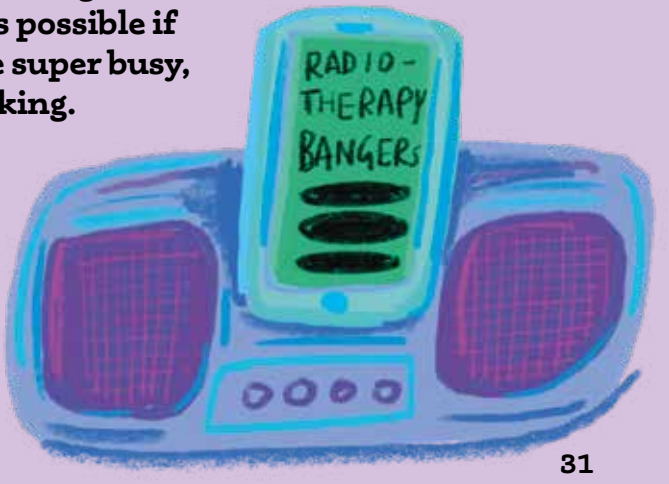
This process is time-consuming and requires input from various professionals, including doctors, physicists and radiographers. This is why it can take a few weeks to plan.

TREATMENT

While the machine is on, you will have to be alone in the treatment room.

The radiographers will put you into the same position you were in for your planning scan, with your mask on. The radiographers and anyone with you will then have to leave you alone. It is important you stay still and breathe normally.

If you would like to see the treatment machine before treatment starts, ask the therapy radiographers in your planning session to organise this. This is not always possible if the machines are super busy, but it is worth asking.



The radiographers will be watching you on cameras outside. If you need them, wave. Before treatment begins, images will be taken to check your position is correct.

It is common to make minor adjustments. Once the radiographers are happy with your position, they will deliver the treatment. You will hear a buzzing sound when the machine is on. You may wish to bring some music to listen to while you have your treatment.

SIDE EFFECTS OF FRACTIONATED RADIOTHERAPY

Side effects vary for each person. You may not feel any side effect for the first week or so. This is a short list of side effects. Your doctor will go through each of these in detail.

As treatment progresses, the following may happen.

HAIR LOSS

Not everyone will lose their hair. If there is hair loss, it is in the treatment area and is gradual. It thins and then becomes patchy. Losing your hair may make you more sensitive to temperature change. Chemotherapy may cause hair loss, but not all kinds of chemotherapy do. Your hair will have staggered regrowth and may grow back feeling slightly different and patchy.

Please speak to your specialist nurse if you are worried about hair loss. Many hospitals also work with charities that donate wigs. Or treat yourself to a new hat or scarf!

NAUSEA AND VOMITING

You may or may not experience sickness and nausea. This can be due to radiotherapy or chemotherapy, or a combination of both.

Your doctor may wish to give you some anti-sickness medication as a precaution or if you develop this symptom.

Mention how you are feeling to your doctor or radiographers.

THRUSH

You may notice that your mouth is sore. Thrush is a side effect associated with chemotherapy or other medication, such as steroids. **Tell a nurse, who can provide medication to alleviate this.**

KEEPING HYDRATED CAN HELP

EAR CONGESTION

If the beam is passing through your ear, it can become dry and irritated towards the end and beyond your treatment. You may notice the ear is 'leaking'. **Again, see your doctor, who can provide ear drops.**

SENSITIVE SKIN

Radiotherapy can make your head red, dry and tender. The radiographers will recommend a skincare routine on your first visit.

Some areas may get a bit more sensitive than others. For example, if the beam is passing by your ear, it can cause the skin behind the ear to feel moist and sensitive.

If you notice your skin is starting to break down, stop using a moisturiser around that area and let the radiographers know. They will have dressings and alternative ointments to use.

Radiotherapy makes the skin sensitive to the sun, and occasionally the sun does shine in the UK! For this reason, make sure your head is protected from the sun. Pop a hat or cap on when you are outside.

But please do not use sun cream while you are on treatment, as the products in sun cream can react with the radiation and increase the risk of sore skin.

The treated area can remain sensitive for a year or longer, so it is important to keep your head protected. Once your skin has settled down, you can start introducing high-factor sun cream (please consult your clinical team before you start using these).

You may feel run-down during your treatment. It takes over the body in swarms. Some days will be better than others. Particularly following your treatment, make sure you rest and let your body recover. It may take months before you get back on your feet, but slowly increase your physical activity and keep hydrated.

If you are struggling with fatigue, email hello@brainstrust.org.uk, and we can send you our fatigue toolkit.

WEIGHT LOSS

It is possible you may lose weight. A full meal may not appeal to you. Just make sure you eat a little.

Ask to speak to a dietician if you are concerned about your weight.

BRAIN SWELLING

Sometimes, but not often, radiotherapy causes brain tissue to swell. This can cause headaches or an additional pressure in your head. The healthcare team will watch for signs of swelling. They can provide medicine to reduce any discomfort. Although rare, this side effect can cause headaches, nausea and seizures.

Call your doctor immediately if you experience any symptoms that are new or different.

LATE EFFECTS

Radiation to the normal brain can cause effects years after treatment. These are called late effects. Late effects are dependent on the location of your tumour.

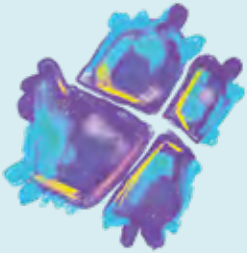
These effects can include impairment in growth, memory, vision, mobility, concentration and higher mental functions. Any late effects that could potentially impact you will be discussed by the doctor, and support is available for their management.

RADIOTHERAPY FOR BRAIN + SPINAL TUMOURS

Brain tumours rarely spread to other parts of the body. However, they can spread within the brain and through the fluid surrounding the brain and spinal cord. You may hear the brain and spinal cord often referred to as the central nervous system (CNS). Some common CNS tumours are astrocytoma, ependymoma and medulloblastoma.

ASTROCYTOMA

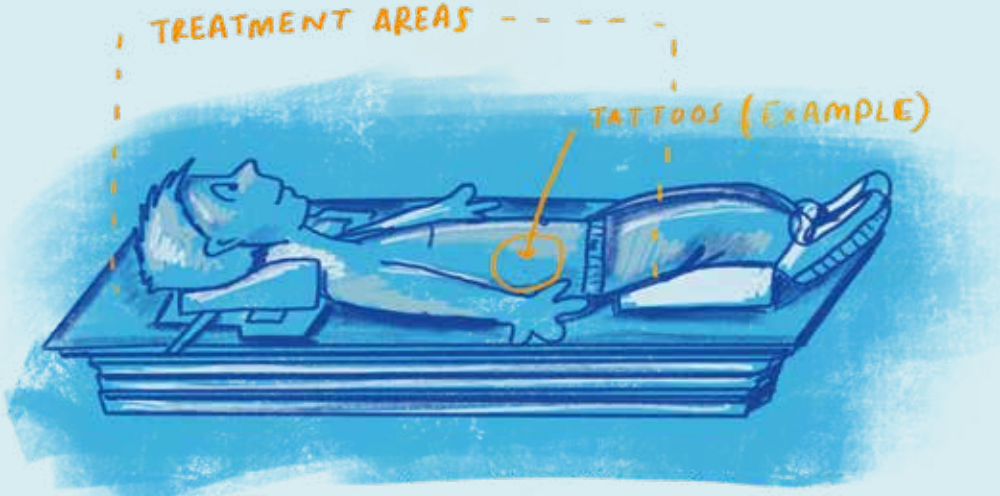
EPENDYMOMA



MEDULLOBLASTOMA

Radiotherapy to the CNS can be referred to as craniospinal irradiation. If you are expected to have CNS radiotherapy, your treatment mask will extend from the top of your head down to the middle of your chest. This is to keep your upper spine straight by preventing your shoulders, neck and head from moving.

To prevent your lower spine from moving, you may need to have some small, permanent skin markers around your waist. These may also be referred to as tattoos and are made on your planning appointment. This involves a small drop of ink placed on your skin, and a small piercing of the skin's surface is done with a needle. You will feel a sharp scratch, and it is over.



For this treatment, you will have to remove your clothes. You will be provided with a gown to keep covered as much as possible during the treatment. This is to allow the radiographers to see the tattoos and to make sure you are aligned correctly for treatment.

If you have any questions about this process, just ask the therapy radiographers.

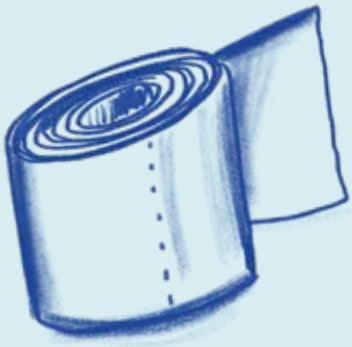
The treatment is more complex, and the machine will move to multiple different positions to deliver the treatment. Talk to your doctor and therapy radiographers. They will explain the treatment plan and duration in more detail with you.

ALL THE SIDE EFFECTS LISTED PREVIOUSLY STILL APPLY FOR CRANIOSPINAL IRRADIATION

SKIN

The skin over your spine, where the radiation enters, and on your chest and stomach, where the radiation exits, may become sensitive.

DIARRHOEA



The lower part of the spine (lumbar spine) is close to the bowel. Due to this, the radiation can cause loose bowel movements and irritation. Please mention this to your team, and they can provide some anti-diarrhoea medication.
If you are suffering from diarrhoea, it is important to keep your fluids up, whether it is water, squash or warm drinks. Try and aim for two litres a day.

2 LITRES A DAY

SORE THROAT

The upper part of the spine (thoracic spine) is close to the throat and may get dry two weeks into the treatment. You may find it difficult to eat or swallow due to the dryness. If you are struggling with this, ask for a referral to a dietician, who can help with the change of appetite and food texture.

STEREOTACTIC RADIOTHERAPY (SRT) AND STEREOTACTIC RADIOSURGERY (SRS)

Stereotactic radiotherapy (SRT) is a type of radiotherapy treatment used to treat some brain tumours. Stereotactic radiotherapy can be delivered through a specialised linac or by other machines, known as CyberKnife or Gamma Knife.

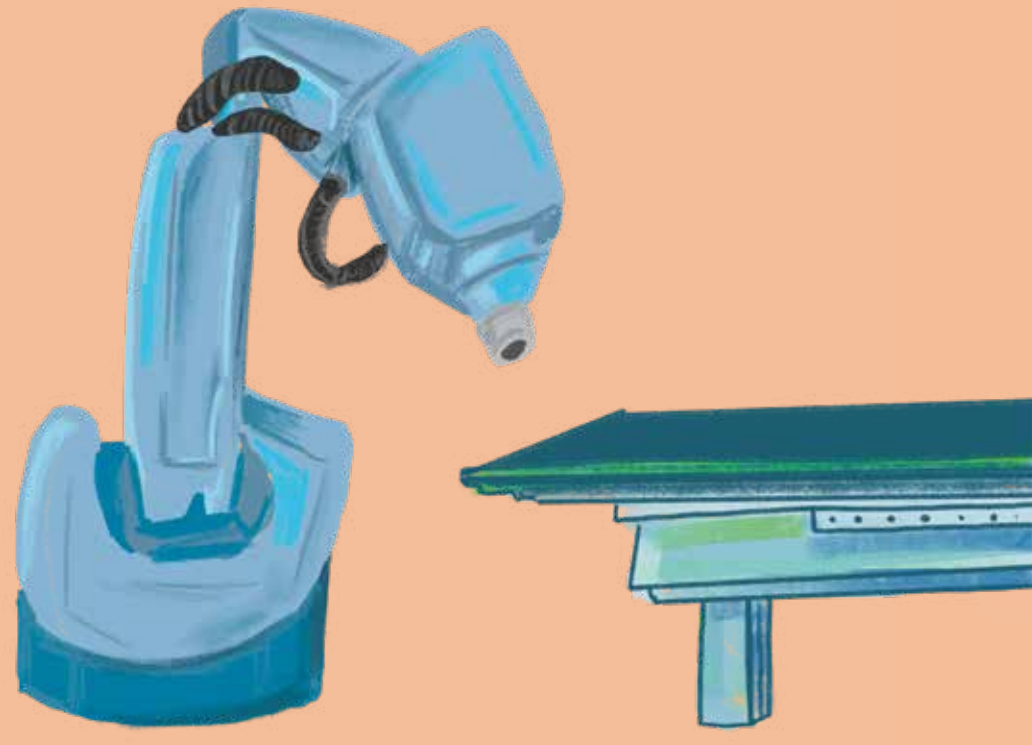
Stereotactic radiotherapy is usually delivered in a small number of sessions spanning several days or even a few weeks. How many fractions, or daily treatments, will depend on the tumour type and fitness of the patient.

If stereotactic radiotherapy is delivered in one session on the same day, then it is known as stereotactic radiosurgery. This is used for small tumours, usually much smaller than 4 cm in diameter, that are well contained.

Radiosurgery can be used for primary brain tumours, small secondary brain tumours and for people who can't have brain surgery due to other medical conditions.

GAMMA KNIFE AND CYBERKNIFE

Stereotactic radiosurgery delivers a focused dose to the tumour, and a limited dose of radiation outside the tumour area. Gamma Knife, CyberKnife and linac-based X-Knife can offer these treatments. These terms for treatment machines are the commercial names, like Hoover is for vacuum cleaners.



WHO CAN HAVE RADIOSURGERY?

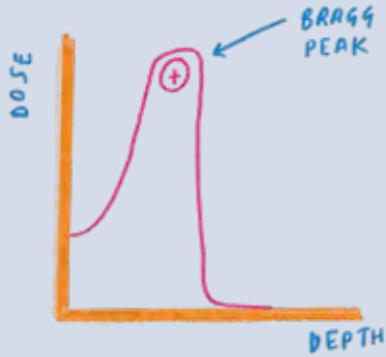
You are most likely to have radiosurgery if you have a tumour that is less than 4 cm across and well defined. Specialists don't recommend radiosurgery for larger brain tumours, because it isn't possible to get the same dose of radiotherapy throughout the treatment area with a large brain tumour.

ACCESSING RADIOSURGERY

Your consultant will discuss your treatment options with you. They will explain which type of treatment would be best for your condition. If it is thought that radiosurgery is the optimal treatment for you, then you will be referred to a centre where radiosurgery is carried out.

PROTON BEAM THERAPY

What is it?
This is a type of radiotherapy that uses high-energy beams of protons to irradiate a tumour. Proton beams are calculated to land at the site of the tumour.

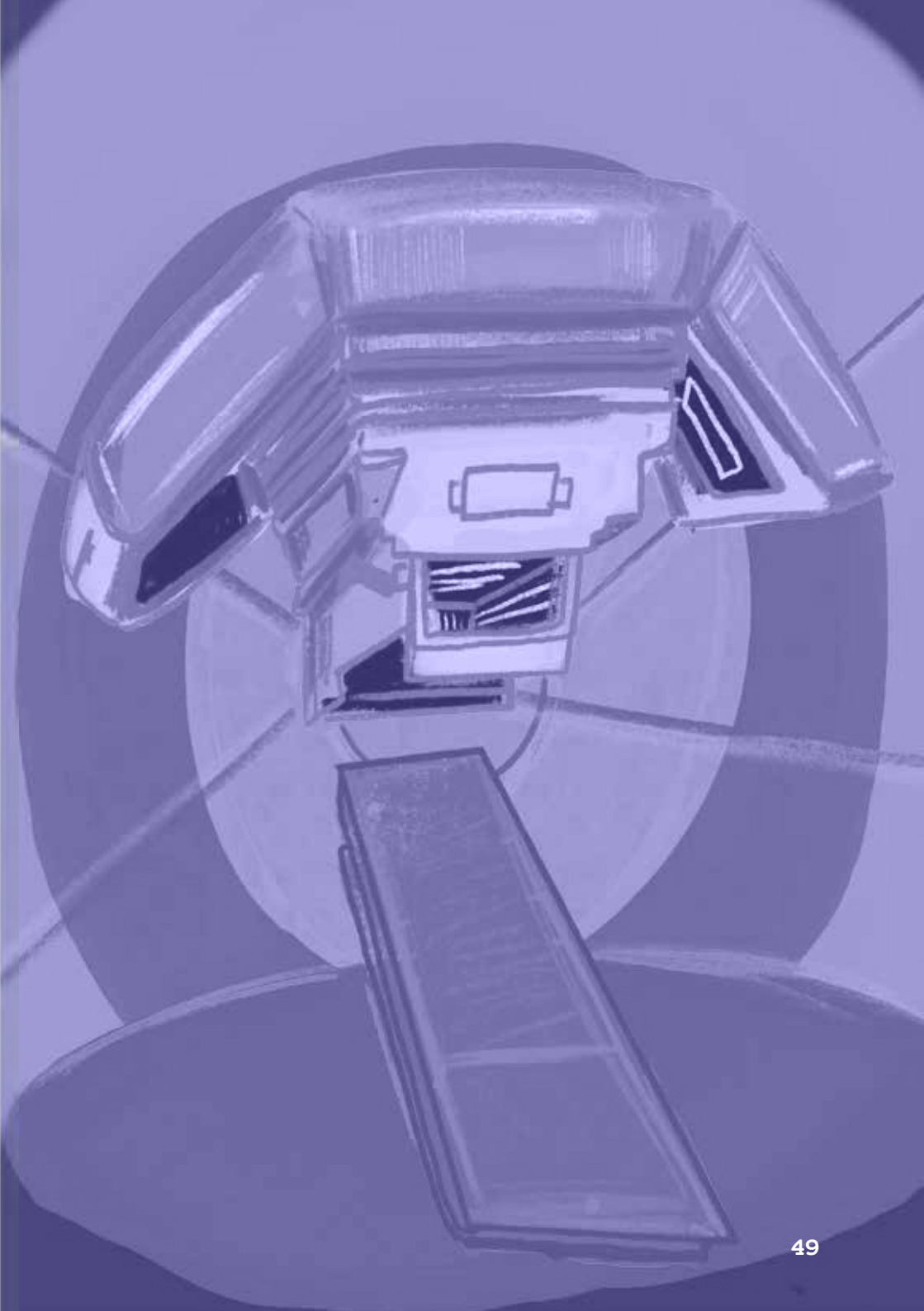


This means the maximum dose of the proton beam is given to the tumour, with only a small dose to the healthy tissue beyond the tumour.

We have specific guides to talk you through proton beam therapy. The proton beam therapy guides have been created to help people:

- feel more confident about PBT
- be more informed and engaged in their situation
- either be assured they are on the best care pathway or feel comfortable and confident in exploring further options
- understand how *brainstrust* can help
- know where further help and information may be available to them.

Our proton beam therapy guides can be found on our website: www.brainstrust.org.uk/proton.



READING LIST

Radiotherapy
https://brainstrust.org.uk/downloads/My-radiotherapy-book.pdf

Proton beam therapy
brainstrust.org.uk/brain-tumour-support/resources/downloads/pbt

GLOSSARY

Here are some definitions of words that you may come across during your treatment. You won't hear all of them; many will not be relevant to you.
For a more comprehensive glossary, visit brainstrust.org.uk/glossary.

GENERAL WORDS

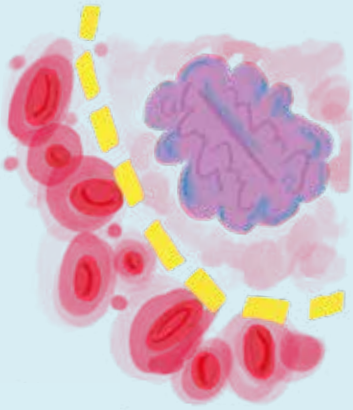
Adjuvant
Usually used in 'adjuvant therapies', these are additional therapies added on to the primary treatment.

ADJUVANT

Asymptomatic
If you are asymptomatic, it means you don't have any symptoms.

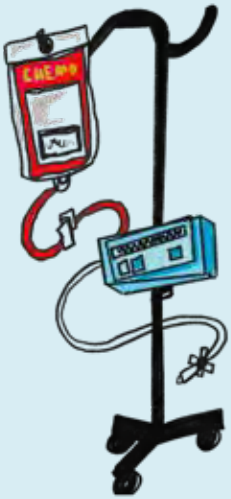
ASYMPTOMATIC

Biopsy
A medical test performed by a surgeon or an interventional radiologist, who will take a sample of cells or tissues for examination.



Blood-brain barrier
A barrier between brain tissue and circulating blood. It is there to protect the brain and prevents substances from leaving the blood and crossing into the brain tissues.

Cerebrospinal fluid (CSF)
A watery fluid that is continuously produced and absorbed, and that flows in the ventricles within the brain and around the surface of the brain and spinal cord.



Chemotherapy
Drug therapy for cancer.

Concurrent
Happening at the same time. Radiotherapy and chemotherapy are often referred to as concurrent when they are given at the same time.

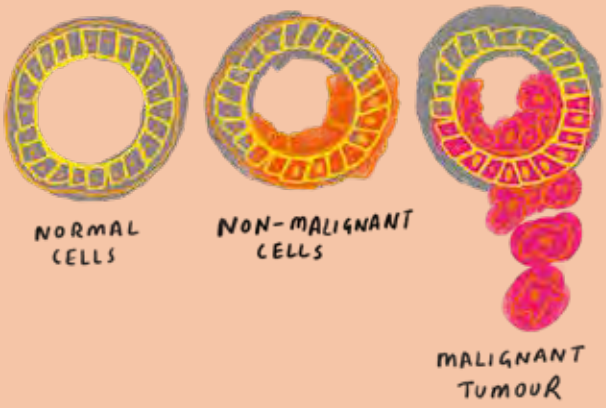
Cyst
Brain cysts are called neoplasms and are made up of natural brain matter, or they may represent more serious problems in the brain that need the attention of a neurologist.

End of life
A phrase used to describe a phase of illness that has become advanced, progressive and incurable.

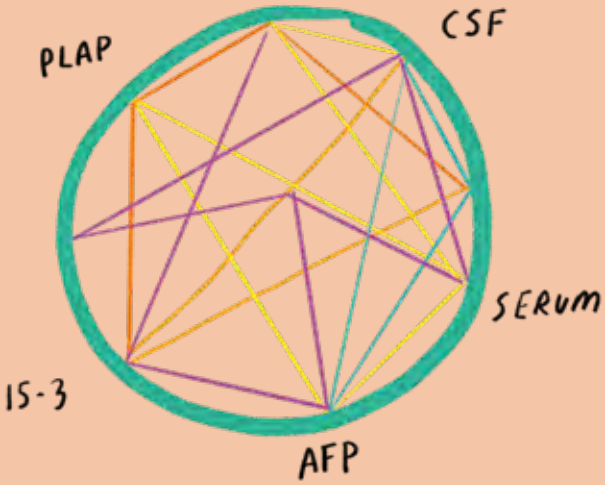
First-line treatment
Initial treatment of an illness.

Grade
A brain tumour will be given a grade that refers to the way the cells of the tumour look under a microscope. Grade I (low grade) refers to tumours that appear less likely to spread, and grade IV (high grade) refers to tumours that appear to grow more quickly or are malignant.

Localised
Confined or restricted to an area.



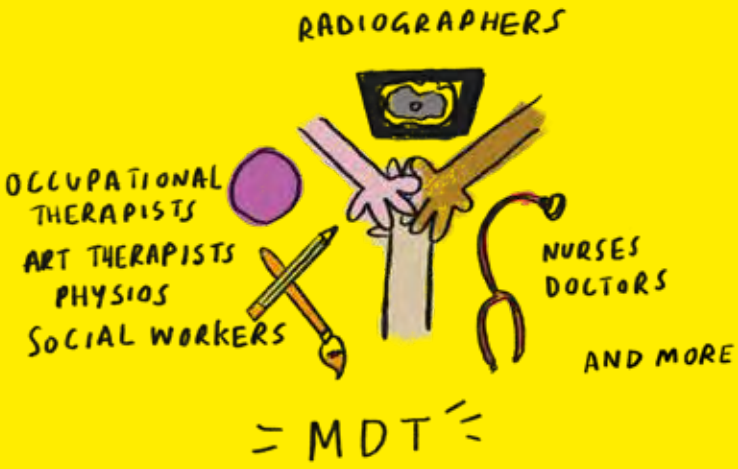
Malignant
Cancerous, tending to invade normal tissue or having an increased risk of recurrence after removal.



Marker
Pathologists can test for markers in the tumour tissue.

Markers can be genetic, molecular or immunohistochemical. These tests can:

- aid the diagnosis of brain tumours that are sometimes hard to diagnose
- allow clinicians to work out a prognosis
- indicate whether a tumour will respond to a specific type of treatment.



Multidisciplinary team meeting
A meeting where different professionals and specialists talk through the best treatment options for each patient.

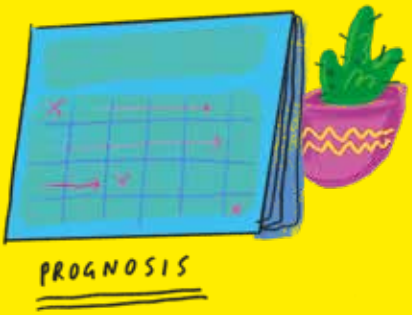
Metastatic brain cancer
A secondary brain tumour formed of cancer cells that began elsewhere in the body, e.g. lung, breast, colon, kidney, skin.

Neuro-oncology
The branch of medical science dealing with tumours of the nervous system.

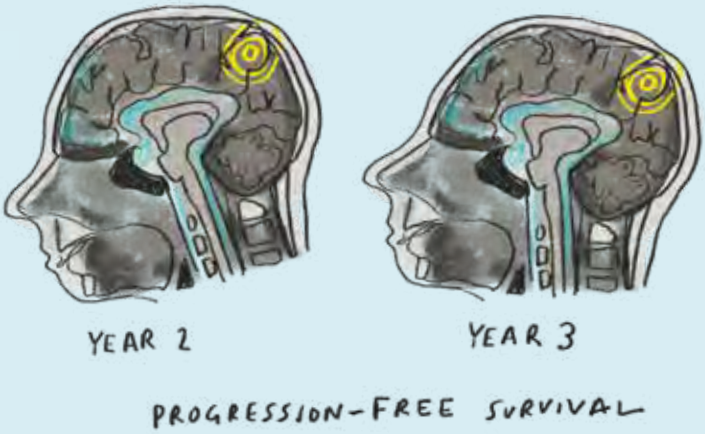
Non-malignant
Slow-growing and not likely to spread.

Overall survival
The percentage of people in a study or treatment group who are still alive for a certain period of time after they were diagnosed with or started treatment for a disease.

Palliative
Relating to the relief of symptoms and the improvement of quality of life.



Prognosis
Forecast as to likely outcome; the chance of recovery.

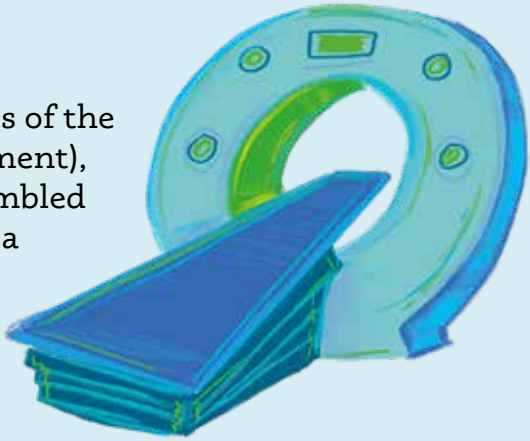


Progression-free survival
The length of time during and after the treatment of a disease that a patient lives with the disease but it does not get worse.

WHO
The World Health Organization classification for the grading of brain tumours.

IMAGING

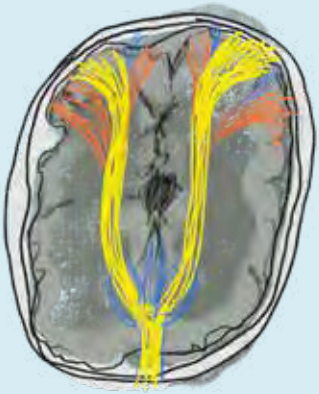
CT (computerised tomography)
X-rays are aimed at slices of the body (by rotating equipment), and the results are assembled with a computer to give a 3D picture of your internal organs.



CONTRAST

Contrast
Sometimes a contrast dye is injected during a CT or MRI scan. The dye helps the radiologist see certain areas more clearly. It helps show what is normal tissue and what could be a lesion.

DTI (diffusion tensor imaging)
A refinement of magnetic resonance imaging (MRI) that allows the doctor to measure the flow of water and track the pathways of white matter in the brain. DTI is able to detect abnormalities in the brain that do not show up on standard MRI scans.



EEG (electroencephalogram)

A record of the tiny electrical impulses produced by the brain's activity. By measuring characteristic wave patterns, the EEG can help diagnose certain conditions of the brain.

Functional MRI

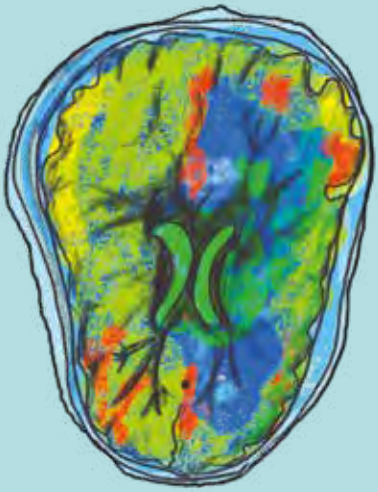
Functional MRI takes the map obtained with traditional MRI imaging, and adds on additional dimensions, such as measuring regional blood flow over time, or something about the biochemistry of brain tumour tissue in a specified location in the brain.

Gadolinium

A substance that enhances tumour images using magnetic resonance imaging (MRI).

iMRI
The use of high-resolution intraoperative magnetic resonance imaging (iMRI) to clearly see brain tumours while performing surgery.

MRI (magnetic resonance imaging)
A special radiology technique that takes pictures of internal structures of the body using magnetism, radio waves and a computer.



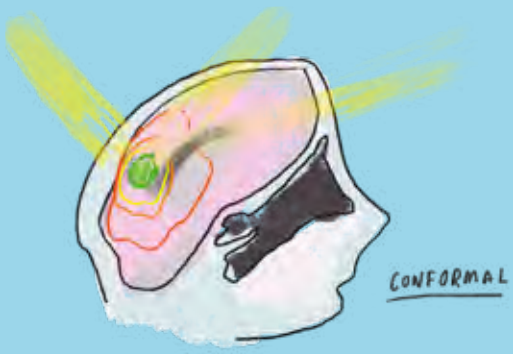
Perfusion MRI
A special type of MRI that uses an injected dye in order to see blood flow through tissues.

PET (positron emission tomography)
A PET scan produces detailed 3D images of the inside of your body. It can show whether lumps are cancerous, whether cancer has spread and where cancer treatment is working.

SPECT (single photon emission computed tomography)
A nuclear imaging scan that integrates a CT scan and uses a radioactive tracer to produce a 3D image of your organs and see how they work.

RADIOTHERAPY

Conformal
This refers to radiotherapy beams that are shaped in three dimensions to match the shape of the tumour.

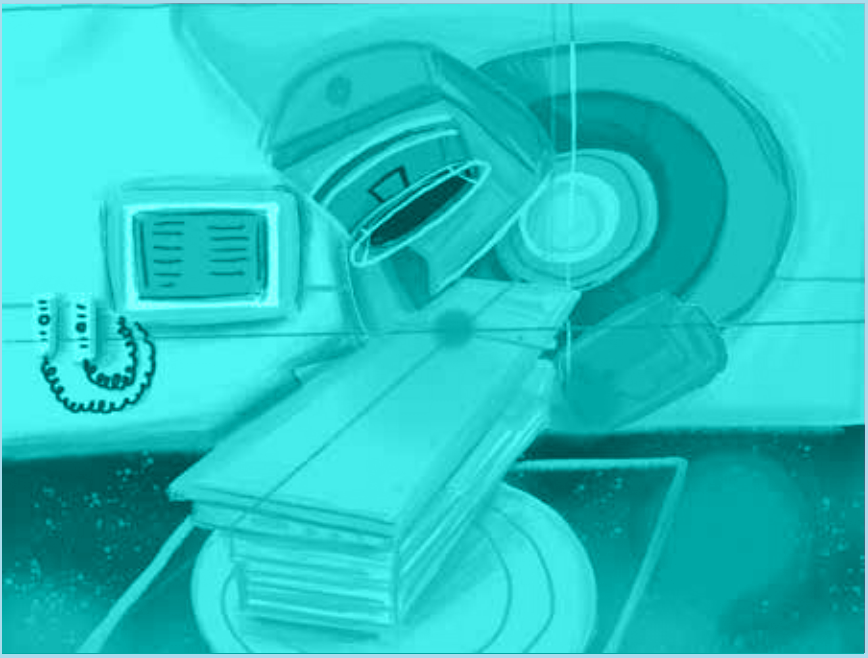


CyberKnife
Brand name of a machine used to deliver linear accelerator stereotactic radiosurgery.

Dose
The total amount of ionising radiation absorbed by material or tissues, expressed in grays (Gy).

Dose rate
The quantity of a treatment given over a period of time.

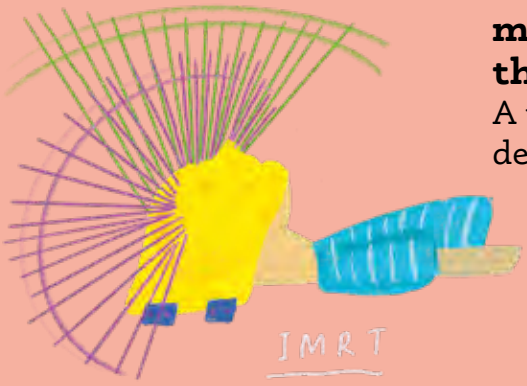
External beam
Radiation therapy that uses a machine to aim high-energy rays at a brain tumour.



Fractions
The total dose of radiation is divided into smaller doses to be delivered over a period of days. These small doses are known as fractions.

Gray
Unit of absorbed ionising radiation dose.

Gamma Knife
Brand name of a machine used to deliver stereotactic radiosurgery (SRS), a focal form of radiation therapy.

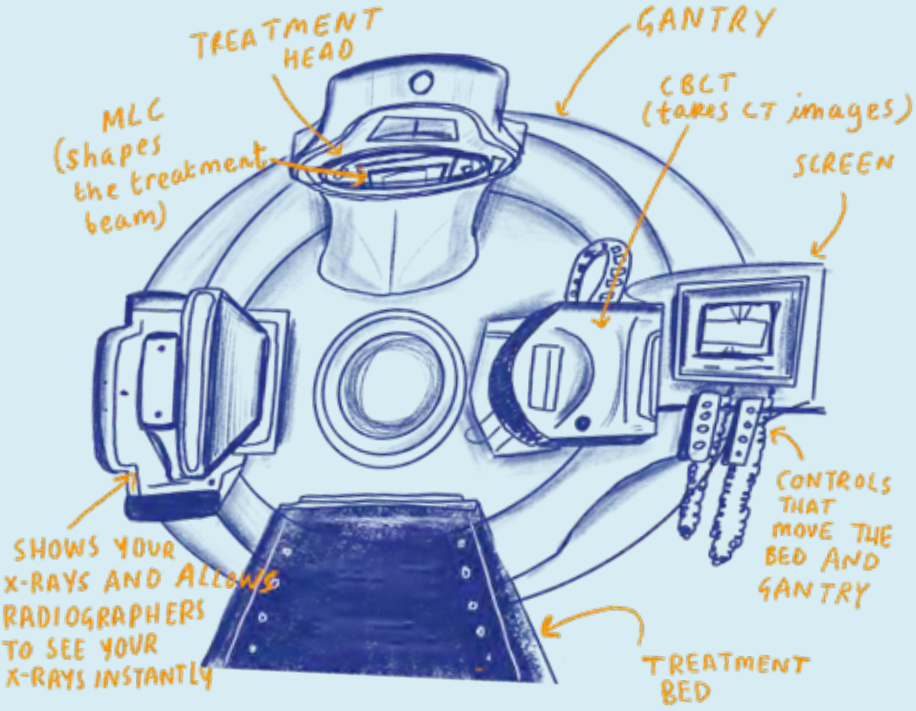


IMRT (intensity-modulated radiation therapy)
A type of radiotherapy delivery where shielding shapes radiation beams to the size and shape of the tumour.

Late effects
A health problem that occurs months or years after a disease is diagnosed or after treatment has ended.

Linac (linear accelerator)

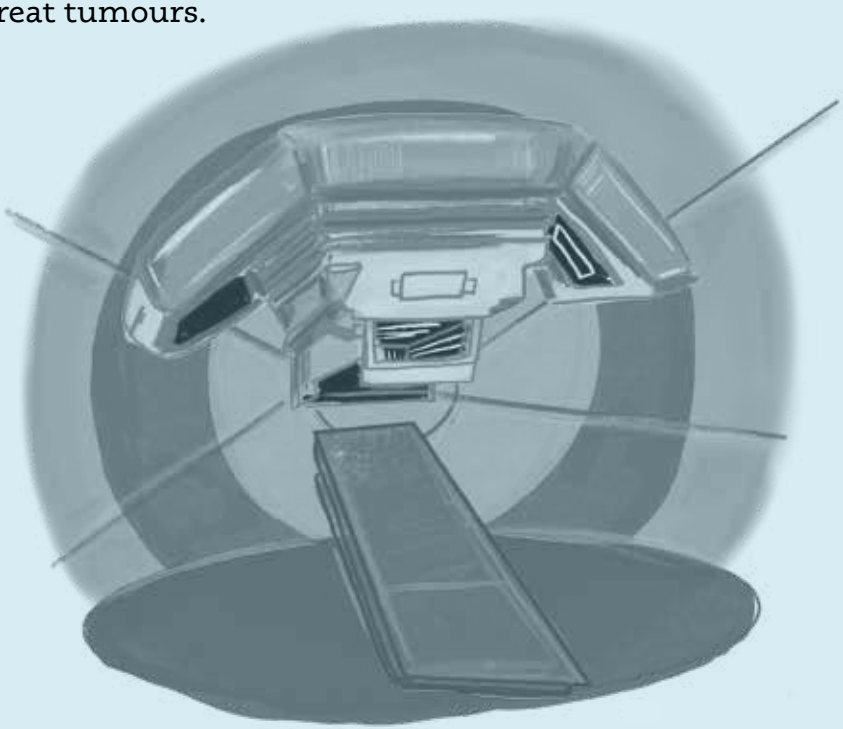
A medical device that creates ionising radiation in the form of X-rays (photons). The machine that delivers radiotherapy treatment is called a linac.



Mask

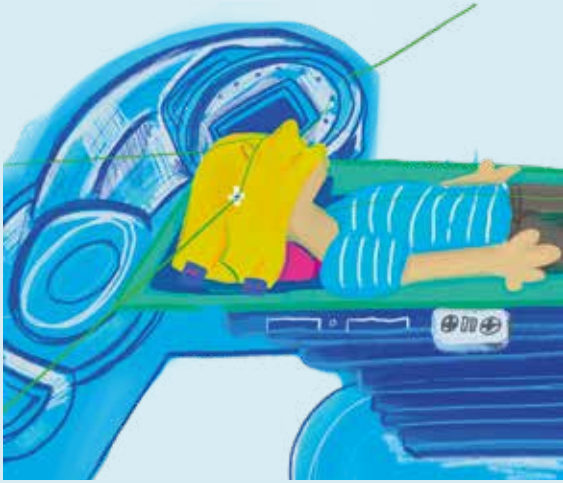
A mould to keep your head from moving so that you are in the exact same position for each radiotherapy treatment.

Proton beam
A high-energy radiation beam of protons to treat tumours.



Whole-brain radiotherapy
A type of external beam radiotherapy that is given to the whole brain over a period of weeks.

Sometimes over one week for palliative radiotherapy.



Contact Details

If you would like any more information about *brainstrust* and how we can help, or would like to organise an event or have suggestions for the trustees, please contact HQ.

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Facebook support group for brain tumour community:

www.facebook.com/groups/braintumoursupportbrainstrust

Facebook support group for parents and caregivers:

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Written in accordance with *brainstrust*'s rigorous production and review process with the input of expert healthcare professionals, patients and caregivers.

This guide is invaluable to you if you want to understand more about radiotherapy.

This guide was illustrated by Sarah Smizz, an artist, researcher and qualified therapeutic radiographer. She is passionate about making healthcare information accessible, engaging and compassionate.

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